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October 19, 1970

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IN REPLY REFER TO: 126B

Father Thomas J. Carroll, Executive Director
The Catholic Guild for All the Blind
770 Centre Street
Newton, Massachusetts 02158

Dear Father Carroll:

Attached is a draft of a working paper on the psycho-social adjustment of veterans with low vision prepared by Dr. Edward J. Glass, Psychologist for the Center. Dr. Glass prepared this paper in response to the question "Is the psycho-social adjustment of veterans with low vision different from that of veterans who are totally blind, and if so, how?"

I think I would be able to get this paper mimeographed prior to the Conference if you feel that it would be useful to have it distributed to the participants. Alternatively, we could furnish copies of it to the discussion group chairmen. Please let me know what you think.

I should be able to get a copy of the agenda to you pretty soon. Look forward to seeing you.

Sincerely,

L. E. APPLE, Chief
Western Blind Rehabilitation Center

Enclosure

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A Working Paper on the Social Psychological Adjustment to Low Residual Vision

by

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The following is a working paper describing observable characteristics of seriously visually impaired low residual vision (l.r.v.) individuals as observed at the Western Blind Rehabilitation Center (WBRC) during a three-year period. The statements should be viewed as propositions for testing and less as assertions based upon verifiable data. Where possible, indicators of variables are explicitly stated. Finally, the statements are exploratory in nature and thus are presented for the purpose of raising questions rather than for the purpose of presenting proof about the behavior described.

The characteristics of l.r.v. which will be described relate to the following: cultural values, family, residence, age, occupation, level of education, role learning, organismic involvement, thought processes, personality, dependency, annoyances, self-rejection, insecurity, adaptation, and Center program experiences.

Sight Loss and Cultural Values

It is proposed that following the onset of sight loss, some of the learning experiences for the l.r.v. individual are on a trial and error basis, at which times there tends to be an excess of definitions of behavior based on social roles derived from an archaic, largely invalid, traditional conception

of the abilities of the blind. Other learning experiences tend to occur in terms of influences conceptualized as guided trial and error. In these there is an excess of definitions of the abilities of the blind which are based upon social roles derived from contemporary valid knowledge regarding human potentiality of visual, tactual and olfactory perception. In this conception it is assumed that in addition to variations in individual capacity, differential role experiences in terms of an excess of associations with the traditional view or contemporary view or combinations thereof, in large measure contribute to the observable differences in the population of l.r.v. individuals. Since the individual develops in the context of social and cultural values regarding disabilities, he brings into his new condition of low-residual vision knowledge which reflects these values. For example, in Spanish-American or Mexican-American ethnic groups the values implicit in the concept of "Machismo" interact upon the view that the male takes of himself as the leader of the family, as the masculine symbol, and the authoritative figure. Total or partial loss of sight chips away at his former position and is substituted by a dependent role. Similarly, other cultural values influence the view of ethnic groups such as the American-Indian, Chinese-American and Japanese-American. One indicator of this factor is nationality.

Another example of cultural influence may be found in the urban-rural dichotomy. A characteristic of l.r.v. individuals from the small town is the more ready acceptance of the traditional role of the blind person. The important consideration in this factor is the extent of urbanization of the community climate in which the individual resides. The "Urban" individual is not one who is necessarily defined by population size of the community, but rather is one who functions in terms of a relatively industrialized,

cosmopolitan, liberal set of values. This complex of characteristics in a highly mobile society cuts across such boundaries as small town, village or large city. The important factor is the presence or absence of the urbanized complex of attitudes and values. One should expect however, to find a larger proportion of less urbanized individuals in the small, rural community than in the suburban or agricultural community near the large city. One indicator of this factor is residence.

Sight Loss and Social Position

The younger l.r.v. individual may tend to overestimate degree of improvement in vision. The older (early middle age) person tends to deny amount of remaining vision because his productive years appear to him to be greatly shortened. His former occupation, through retirement or pension, provides him with a source of income related to absence of sight, which, if improved, would probably jeopardize his income. In addition, his role as the provider has already been challenged and he links his retention of his role to the pension or retirement income. There are exceptions in the younger age group associated with cultural sub-group, level of aspiration, and reference group with which they tend to identify. One indicator of this factor is age grade.

Marital discord, separation and divorce may be characteristic of persons experiencing low residual vision. A decrease in income often shifts the role of the provider to the other spouse with a consequent shift from a dependent to a more independent position in the family for the normally-sighted spouse. There is a simultaneous modification in the conception of the disabled individual by other family members that takes a toll upon authority, decision-making, planning-function, and responsibility. The single person with l.r.v. finds himself in competition with the majority sighted population for a sighted

spouse. There is a tendency to select one's mate from the older, divorced, or widowed segment of the population. Although this tendency is also true for the younger, single male, he also tends to be very concerned about the reaction of former girl friends, or his favorite dates toward his disability. Unsuccessful experiences will often cause him to shift focus to other marital status categories: divorced, widowed, etc. One indicator of this factor is marital status.

There is a tendency to place a high value upon retaining those gains which were made during the former working years. Events which jeopardized the ownership of home become very anxiety-producing since the individual is less able to replace it as a handicapped person. One indicator of this factor is extent of home ownership.

Persons who have completed high school or some college feel more confident about overcoming an l.r.v. handicap than persons with lower grade education only. Persons with primary school education only, are interested in remedial study to raise their academic level, whether it be to increase personal satisfaction or to improve their chances for vocational training. Low residual vision individuals may tend to be more accepting of education therapy to correct literacy problems than are totally blind individuals with the same educational deficiency. One indicator of this factor is years of schooling completed.

Sight Loss and Role Learning

When l.r.v. occurs, the individual finds that activities which were formerly casual and automatic now involve more concentration, time and effort. For example, dialing a phone, completing a purchase at a supermarket, purchasing a ticket at a movie, managing his personal effects, selecting clothing, shaving, etc. There tends to be considerably more involvement of body systems in

controlling himself in relation to objects, events, activities, and situations. Ordinarily, most of an individual's daily functioning in these areas is organized in ways that require minimal affective, motoric, autonomic, glandular, etc. body systems. There tends to be minimal connections between the activities and the self. Often times the individual performs these public or private activities while simultaneously imagining himself in totally different situations through day dreaming or fantasying. When a disproportionate amount of daily functioning is directed in terms of intensive organismic involvement there are consequences upon the expenditure of physical energy, level of stress, and body tension. There may also be consequences upon learning of new social roles, personality formation and role enactment.

The l.r.v. individual experiences problems in role learning. This may result from the inaccessibility of his own behavior to himself due to intensive organismic involvement. Accessibility refers to the reportability of role enactment or the extent to which the individual's role behavior is available to his own self-reactions (Sarbin (1966)). This carries the connotation that the individual cannot make valid observations of his own role enactments under some conditions. For example, when traveling in a busy downtown business section, the individual's organismic involvement is relatively more intensive when avoiding danger, in identifying formerly familiar objects, in identifying landmarks and in maintaining orientation. Thus, in being greatly involved in the organismic features of the role enactment, probability of reflecting upon himself as a social object who is performing in an activity is greatly limited.

The l.r.v. individual's ability to engage in hypothesis testing or "as if" behavior is decreased when sight loss occurs. "As if" behavior refers to the ability to treat an object or event "as if" it is something else and to

hold the conception in mind while attempting to group apparently disparate objects or events into a common concept. The person must hold the thought or maintain the set established by the problematic event while at the same time considering the independent object or event. The learning of new social roles, the maintenance of stability and personality as well as meaningful personality change are seriously retarded when the individual is unable to respond to himself as a social object. Similarly, the ability to engage in "as if" behavior as other abilities, is probably greatly reduced when the individual experiences stress and anxiety. It may be that skill and relaxation training is important as a corrective technique to provide the conditions for "as if" behavior.

Sight Loss and Perception of Changing Roles

Two types of relationships are relevant in understanding the personal and social adjustment of the low residual vision individual: A-the relationship between the individual and physical stimuli; B-the relationship between the individual and other individuals in the enactment of social patterns or social roles. Prior to loss of sight the individual learned characteristic modes of adaptation to physical stimuli and social patterns. At the onset of sight loss readaptation in both areas becomes necessary. Individuals have large numbers of these relationships and are continuously establishing new ones or revising old ones. The content of the interaction between the individual and physical stimuli and social patterns becomes disfunctional when l.r.v. occurs and like his perceptions of the form of the physical stimuli, both the individual's self reactions and responses of others in the social pattern tend to change as a result of the change in visual acuity that he has experienced.

Thus a different ordering of the man-social pattern relationship is required. When the l.r.v. individual perceives the social pattern in terms of a previous learned conception, inaccuracies in the reciprocal responses of others occur. Cultural values in our society dictate that serious loss of sight necessarily has a corresponding loss of functioning in social relations. Because the position of the l.r.v. individual characteristically changes downward in the hierarchy of positions in the structure, there is often a corresponding adaptive change in the roles of others in the structure. The process of readaptation of persons in the patterned relationships consists of the modification of expectations, but since there tends to be a relative absence of knowledge by individuals about adaptation to l.r.v., adaptation tends to be random and on a trial and error basis. Modifications do occur in role behavior, but since they are largely on a trial and error basis, maladaptive behavior by the l.r.v. individual increases, tensions become greater, and frustrations accumulate. For example, l.r.v. individuals experience a change in their role of importance in the family, on the job and in the neighborhood. Responsibilities tend to be shifted to the older son or daughter or are assumed by the spouse. The individual's knowledge about family matters, especially in the financial area, tends to decrease as his role in decisions decreases. If he continues in his former work serious misunderstandings, blame, breakdown in communication, feeling of being watched, loss of promotional opportunity, etc. add to feelings of insecurity and loss of status occurring at home. His perceptions of himself and perceptions of others may become unstructured for a time, however, restructuring often occurs in faulty and erroneous ways which resemble delusional patterns found in the typical paranoid. In the family, physical conflict with the children as well as the spouse may occur due to

frustration and extreme insecurity, all of which reacts back upon the individual's decreasing effective role as a significant person in the family. Job insecurity and decline in confidence among fellow workers and by the employer further adds to the vicious cycle of loss of functioning, insecurity and anxiety, further loss of functioning in important roles, lack of structure in relationships with others, distorted perceptions, additional insecurity and anxiety, etc. Permitted to continue, the experience may easily deteriorate into extreme personal and social problems. It is not so much that disorganized behavior occurs but rather the patterns of relationship become unorganized or in time disorganized when the discord and conflict take shape as consistent modes of interaction.

Lack of congruence in the organization of social roles has consequences for the direction of personality change. For example, another characteristic of persons with l.r.v. is a tendency towards symptoms of depression. A decrease of sense of adequacy in the family and on the job adds to the feeling of loss occurring with decrease in vision. In addition, the individual becomes less physically active and more sedentary. The decrease in physical activity, absence of new experiences, and loss of status often results in unaccustomed depressions. On the other hand, when the restructuring of relationships occurs in terms of guided learning, adequate models, opportunity for learning in terms of contemporary knowledge and techniques, repetition, reinforcement and practice of the knowledge and techniques, the chances for success in change in role behavior is greatly increased.

Sight Loss, Personality, and Role Enactment

In this section it is hypothesized that three l.r.v. personality types tend to develop. These should be viewed as ideal types as actual individuals

correspond only to a degree. First, the type characterized by the individual who tends to identify himself as a sighted person and who attempts to "pass" as a sighted person by completely rejecting blindness; second, the type characterized by the individual who uses the blind aspect of his identification to gain "the edge" or the advantage in most of his daily activiites; third, the type characterized by the individual who attempts to learn the maximum use of residual vision as it applies to his total life situation. In learning his limitations and powers of functioning, he attempts to make a valid assessment of when to use the technique-ways of the blind as a sensible adaptation to fulfill his needs.

The l.r.v. individual who has recently experienced sight loss may experience fear about total sight loss. Much of the fear is a consequence of the invalid knowledge he has about blindness. Experiences at a rehabilitation center modify erroneous beliefs. He learns that he can utilize remaining vision. One resulting characteristic at a rehabilitation center is to fill the role of leader and to encourage the establishment of dependency patterns upon him. For example, guiding the blind person, locating a table in a restaurant, having a low tolerance for slowness by the totally blind, etc. He tends to respond with more than normal frequency to other persons, events and external physical stimuli when with the totally blind. Most of the persons, events and stimuli are perceived by limited visual acuity and at times may be inaccurate. Interviews suggest that he may tend to utilize combinations of auditory, tactual and olfactory modalities less than the totally blind, a factor contributing to inaccuracy and error when attempting to be the leader.

The l.r.v. individual experiences annoyances in several areas. Such areas as not being able to drive a car, use of a cane, being identified as a blind

with maximum success occurring when made in terms of its relevance to experienced problem situations. The program is supported when the individual is exposed to situations unrecognized by him as problems. Insight provided by verbal examples are effective when followed by action-oriented experiences in problem situations.

The l.r.v. individual tends to be more suspicious in a variety of situations than the normally sighted individual or the totally blind. The loss of functional roles in the family results in a higher frequency of role performance by other family members in those areas usually performed by the individual. Symptoms of the change in functional roles are: marital discord, jealousy, resentment of his children, paranoid episodes, and anxiety. A decrease in the individual's importance in primary group relations is often accompanied by a parallel decrease in a sense of job security.

Since the l.r.v. individual experiences a decrease in his self-conception as the breadwinner in the family, a characteristic of this group is a greater sense of economic insecurity in comparison to the normally sighted population. Some of the symptoms which are present while employed are: fear of impending loss of work, suspiciousness about fellow employees, feelings of unfair treatment, feelings of unjust blame, loss of eligibility for promotion.

Low residual vision individuals may tend to have concerns about their own personality. They are concerned about characteristic modes of responses manifested by them as sighted persons and their consequences in future situations as disabled individuals. The greatest concern relates to those personality attributes which function unsuccessfully when sighted. He wonders about how he will handle those situations as a low vision person. Not knowing "how to be," or "how to relate to others" produces additional personal

insecurity. He requires opportunity to talk about the situation areas and to work through his part of the interaction so as to improve his understanding. He needs to develop additional self-constructs and other alternative ways of perceiving himself so as to increase his repertory of interpersonal skills.

The l.r.v. individual often tends to control social situations by using characteristics of total blindness. Though often interpreted as "shamming" or "faking" by the public and other blind persons it tends to occur more frequently among those who withhold information about their amount of vision and less frequently among those who feel their vision is improving. It is also related to the phenomenon of "having the edge" frequently observed among l.r.v. individuals. Basically it may reflect an initial uncertainty about how to behave, which, in time becomes resolved by the expediency of appearing to be totally blind. This adaptation may eventually become part of the individual's habit system which is called forth whenever the constellation of related situational stimuli requires. A set of social rewards and penalties accompany the tendency to control situations by "shamming." Rewards take the form of praise from unsuspecting sighted persons who define him as "an unusual blind person." Penalties take the form of a deprivation of rewards for real and valid accomplishments from persons who know his true identity, usually family, friends, and other disabled individuals by attributing his accomplishments to remaining visual acuity.

Related to the foregoing, l.r.v. individuals tend to have a conception of themselves as being a separate group of disabled persons. The self-conception is probably related to the feeling of being "in between" the totally blind and the sighted. Sometimes described by Stonequist's (1937) concept "marginal man" it causes the individual to raise questions about "who am I?" and questions from others about "who is he?"

When the subject of low residual vision is raised, some individuals experience a strain to maintain their identifications as different from the totally blind. Lacking an adequate language to communicate the differences, there also tends to be an increase in level of anxiety, body tension, movement, and heightening of awareness. A partial explanation for viewing himself as different from either the totally blind or the sighted may be that he tends to draw upon sighted models in the shaping of his behavior. In addition, relationships with sighted persons are a fragile dimension of his adaptation because they are the areas in which he is most uncertain and since he in fact does have a serious visual problem, sighted persons are also uncertain about his limitations. He is unable to "pass" successfully but aspires to do so. Sighted persons, in turn, may actually positively reinforce his aspirations to act as a sighted person in some instances, but withhold reinforcement in other areas of role enactment.

As noted, a characteristic of the l.r.v. individual is to experience problems which lead him to reconsider and reject participation in particular instructional areas of a center program. He is usually concerned about jeopardizing his present level of vision by continuing to function in the instructional area. For example, eye strain by typing, sunlight when traveling, brushing against low hanging branches, being injured by falling, aggravating an eye condition by wood dust, etc.

Being overweight and decrease in muscular toneness may be characteristic of the older, l.r.v. individual. Weight gains are linked to decrease in physical activity and increase in anxiety level. One indicator of this factor is height and weight. Persons with l.r.v. tend to express more somatic symptoms than persons who are totally blind. One reason for this may be that the

former gives more attention to health and day-to-day changes in physical well-being because of his great concern about retaining or improving his present level of vision.

The foregoing raises several questions for exploratory research. One, does the adventitiously l.r.v. individual identify with the normally sighted population to a greater extent than the congenitally l.r.v. individual and the adventitiously totally blind individual? To investigate this question however, one needs to ask: Two, What are the roles and tasks in which the adventitious l.r.v. and the congenital l.r.v. individuals most frequently engage when functioning as totally blind persons and as sighted persons? Three, is the adventitious l.r.v. individual more successful in role performance and in tasks when functioning "as if" he is a sighted person than is the congenital l.r.v. individual, i.e. is he able to pass more successfully as a sighted person in roles and tasks than is the congenital l.r.v. individual in the same roles and tasks? Four, are the consequences of such identifications different for the three populations with respect to the following: a. rehabilitation training, i.e. travel training, writing skills, personal management skills, and manual skills b. relations with others during training, i.e. relations with staff, relations with fellow students, demands upon staff c. amount of dissatisfaction during rehabilitation training, i.e. with food, with medical care, with scheduling of time d. cooperation in the rehabilitation program e. family problems arising during the program f. tensions, anxieties and emotional stability during the program. Five, what are the roles and tasks in which the adventitious l.r.v., the congenital l.r.v. and the total adventitiously blind individual identify as sighted persons? Six, what factors differentiate among the adventitious l.r.v., the congenital l.r.v. and the

adventitious totally blind who do identify as sighted persons as compared to those who identify with totally blind persons, i.e. participate in role performance and tasks as totally blind and not as l.r.v. individuals or sighted persons. Seven, what visual memories tend to be salient for the adventitious l.r.v. as compared with the congenital l.r.v. and the adventitious totally blind?

Conclusions

As stated, the above observations are based upon clinical interviews of individuals with l.r.v. Upon loss of sight and in a great many of his trial and error experiences, the l.r.v. individual finds that many of his previous casual involvements are no longer automatic. A great deal of effort in role behavior is involved in quite ordinary tasks and activities with negative consequences for new role learning. To understand the effect of l.r.v. upon the accessibility dimension and the "as if" dimension one needs to consider that prior role expectations in the family, on the job, and in the community become modified in relatively unpredictable and poorly defined ways in the l.r.v. population. At times he persists in responding to others in ways that are no longer relevant or the others continue in their role expectations unmindful that new role behavior is being learned by him. Or, as noted above, the individual is often times so much involved in adaptations to matters of personal management and personal care that experiences involving reflections upon himself become fewer and fewer. It needs to be remembered that both the accessibility dimension and the "as if" dimension involve the use of symbols or language. If the individual's life roles are relatively unstructured it may also follow that important connections between meanings, symbols, objects and events will also be seriously impaired. As in the need to reestablish modes of identification with physical objects and physical events to move

about with improved effectiveness, so too it is necessary to reestablish modes of identification with social patterns, significant others and with onesself. Reestablishing a self identity requires the use of symbols with which to hold in mind the problematic element of his self-concept while working through his adaptations. It may be that there is an absence of an adequate language in this population just as there seems to be an absence of an adequate language to communicate the sensory responses, in object perception among the congenitally blind. During interviews many l.r.v. individuals comment upon the lack of understanding of their problems by others. A frequently heard complaint is that neighbors, friends and acquaintances have often asked a wife or parent "why so and so passed them without acknowledging a greeting." The l.r.v. individual usually pleads "how can I explain when I can see and when I cannot? I don't remember what the day was like, cloudy, rainy, whether I was indoors or outdoors." Loss of hearing can be explained by the term "I am hard of hearing." There is no similar expression for the person with serious visual impairment. The development of skill in the communication of his experiences to family members and the development of a language to facilitate communication would appear to be vital for this sub-population.

Finally, it is important to gather additional knowledge about the cultural definition of sight loss from cultural sub groups within the society. Cultural values influence the perspective from which others view the remaining capabilities of the l.r.v. individual. They also influence the view which the individual himself has about his future development. A grasp of these culturally defined assumptions may add important information to the evaluation of an individual's motivations, plans for the future, family setting and community

acceptance, all of which may be counter influences upon the attitude change, behavior change and personal change occurring at a Center for the rehabilitation of the severely visually impaired.

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